

# Father's Involvement Is Important

*By Patricia Bill*

When the world talks about rearing children, the tone is decidedly feminine. Despite the growing number of fathers in traditional or single parent families who participate in child-care, resources specifically focusing on fathers are often missing. It is especially true for fathers of children with disabilities.

Three Twin Cities men recently acknowledged the lack of materials targeted toward fathers. They offered suggestions, based on their experiences, about how fathers can become more involved in the lives of their children with disabilities.

## **John Guthmann**

Alex Guthmann was an infant when his parents, John and Teresa Guthmann of St. Paul, realized that their firstborn was not developing according to pediatric charts. Shortly thereafter, doctors confirmed that Alex, now 10, has mental and physical disabilities. His rare genetic disorder was not diagnosed until years later.

"There is nothing that can prepare you for the images that accompany the discovery that your child has a disability," John said. "Do not think for a moment that you can go down this road alone or that any experience you have had in life has prepared you to handle it. You are going to have to deal with yourself, the needs of your child, and the world your child faces, all at the same time."

"You look at the world differently when you have a child with a disability. It takes a long time to orient your thinking to having a child with a disability and how it will affect your life. The reality comes as the child grows older," John explained. "You try to lead a normal life, and you do what you have to do. It's often hard for fathers to talk about their child. Most interact with their typical children through sports, school, or other activities. If I want to find a father with my experience, it's very difficult."

"The world makes many demands on fathers," said John. "Factors such as job, the marriage relationship, society's expectations, cultural background, and family traditions affect a father's involvement in his child. If the child has a disability, there are even more demands and factors."

"Your self-image as a father is influenced by roles and traditions," John continued. "You may see yourself, consciously or unconsciously, as a 'provider,' 'hunter-gatherer,' and the 'strong one,' more than as 'child rearer.' To the extent that these roles are valid, they developed to help rear typical children. You need different traditions and roles to successfully father a child with a disability in today's world," John continued.

Both John and Teresa tend to Alex's physical needs, which include feeding and diapering. Teresa works part-time. On those days, John does morning duties, including waking, feeding, dressing, and taking Alex to school or child-care before he reports to work. John and Teresa agree that if John needs to go into the office on evenings or weekends, he takes one of the children (the Guthmanns also have seven-year-old twins) with him. Alex is often the one. "He's very good company. He's good-natured and likes to go places," said John.

In addition to sharing Alex's personal care, the Guthmanns participate in activities that affect him. Teresa is on the board of MELD (Minnesota Early Learning Design). John is a member and former president of PACER's Board of Directors. He is also a member of the Governor's Interagency Coordinating Council (ICC), part of Minnesota's early intervention system, where he affects policymaking. "I believe that by being active in policymaking, you have an impact on your own child, as well as others. I find it very therapeutic," said John.

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Involving parents in the ICC and other committees is a huge problem, John said. Parents are often overwhelmed by what is going on at home and believe they do not have the capacity to take on more responsibility. As a result, policymakers sometimes become used to making decisions without parent input, he said. The adage “The world is run by those who show up” applies to the world of families of children with disabilities, said John.

### **Paul Kempf**

Before Patrick was born, Paul and Jacqueline Kempf learned that their son had a chromosome disorder and would have disabilities. A pediatric nurse, Jacque used professional contacts to arrange for the help Patrick would need. Paul attended all the prenatal appointments with her, making every effort to support her as well as to inform himself.

“Early on, especially before Patrick was born, I made a point of trying to find as much information as possible in preparation,” said Paul. “All your life, you think of the future and becoming a father. You dream about the perfect child you will have. No one dreams about having a child with a disability. When you find out your child has disabilities, there is a certain amount of fear. It takes a lot of emotional energy to adjust.”

Paul was in the delivery room when Patrick, who is now two years old, was born. So was medical support for the little boy with sight and hearing loss, a heart defect, low muscle tone that affects motor development, and a cleft lip and palate. Specialists and other medical staff hurried to examine Patrick and attach him to equipment. Paul said he was glad he had been involved in the prenatal appointments. He isn’t sure how he would have reacted in the delivery room, otherwise.

Paul is involved day-to-day in Patrick’s life. He continues to attend many of Patrick’s medical appointments. He learned sign language, through which Patrick has communicated since he was eight months old, and speaks on the telephone with Jacque about Patrick during the day.

At home, Paul and Jacque agree that the key to not becoming overwhelmed is teamwork. They share in the care of their son, such as following up on therapy, tending to his needs as a toddler, and doing oral

stimulation before feeding (Patrick has difficulty eating solid foods). The little boy has therapy five times a week, including physical therapy, occupational therapy, speech therapy, sign language, and therapy for feeding. Paul reinforces the physical therapy through play in the evening.

“When Paul walks through the door after work, Patrick becomes very vocal and ready to interact,” said Jacque. “He is crazy about Paul.”

Paul is happy to be with Patrick, he said. He looks forward to the “nighttime stuff” for which he is responsible, including preparing Patrick for bed, bedtime stories, and a nighttime bottle, he said. “Patrick is who he is,” said Paul. “One of the first things that gave me peace was a thought that there are certain things in life you can control and some things you can’t control. I’ve given up worrying about ‘How bad is his hearing loss?’ ‘How bad is his eyesight?’ ‘How bad is his heart?’ My role is to support him and do what I can for him.”

### **Brian Walker**

When Malcolm Walker was born, physicians advised his parents that because of the nature of his disabilities, they should place him in a home, visit him periodically, and go on with life.

Eighteen years later, Malcolm and his parents, Brian and Denise Walker, have proved the doctors wrong. Malcolm, who has hydrocephalus, cerebral palsy, and mental retardation is very much a part of his family—and the community. Now in Grade 11, Malcolm enjoys participating in adaptive physical education team sports and swimming. He creates art, currently focusing on textiles. His family calls him the “Computer Whiz Kid” and vows he can locate anything on the Internet. He has worked at a fast-food restaurant and aspires to career in a store where he can work with computers, video devices and other electronic equipment.

“Thank God we ignored the doctor’s advice, and took our firstborn home,” Brian has written. “We stared at him for a couple of weeks, showed him off to friends and relatives, and then began the long, difficult, and, yet, rewarding role of raising a child with disabilities. Least restrictive educational settings, love, discipline, and prayer have been cornerstones in his upbringing.”

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Denise gives much of the credit for Malcolm's success to Brian. She recalled the efforts they made together to assist Malcolm—driving him to another state for the best early intervention (they lived on the East Coast) and sharing in his personal care, such as diapering well into childhood.

Now that Malcolm is a young man, he continues a strong and enduring relationship with his father. Together, they attend sports, church, and social events. They go on an annual fishing trip with a group of other fathers and sons from their church, and have attended Promise Keepers conventions together for several years.

“Brian was very, very involved and instrumental in raising Malcolm, especially in the elementary school years that involved an individualized education program (IEP),” said Denise. “Brian is a magnificent advocate for Malcolm. PACER prepared him. I learned how to advocate, literally, from Brian. Despite a horrific work schedule, Brian *always* made time to attend Malcolm's IEP meetings.”

Now they have man-to-man discussions. That is where the ideas of self-discipline are meted out. We hope that someday Malcolm will marry and support a family, and some of the talks involve sexuality and other issues,” said Denise.

“Constant words of encouragement and love liberally showered upon my son have made a world of difference,” said Brian. In addition, the Walkers made decisions about raising Malcolm based on several principles, some related to their racial background, and some not.

The principles include:

- raising Malcolm according their religious belief;
- raising him like their other children;
- being assertive (not aggressive) and never taking no for an answer in seeking services for him;
- teaching him about his heritage and culture without bitterness and hatred; and
- having fun with him—enjoying him as a person.

The Walkers follow another principle. Brian deals with the schools and other professionals. “Because of the pervasive perception of Black males, it is imperative that Black fathers become the advocate for their son or daughter,” said Brian. “My wife is a very capable and intelligent person. She has a law degree, but it's Dad who goes to all the staffings. It is hard to explain, but there is a different dynamic when the father comes to the IEP meeting. If the father is African-American, the professionals on the other side do sit up and take notice.”

Brian offers additional advice to fathers of children with disabilities:

“Above all, believe only the best, demand only the best, give only the best for you and your child. It is possible to raise a child with a disability in a debilitating world. Many have done it; some of us are still struggling. If we run this race called ‘life’ with endurance, we can and we will reap great dividends, not only for our families, but for our communities as well.”



# Father's Involvement





## Tips for Fathers of Children with Disabilities

### 1. Learn about the disability.

“Know everything there is to know about the disability, including diagnosis and prognosis,” said John Guthmann, “Fear is often the result of lack of knowledge. Knowledge makes it easier to deal with the disability.”

The child’s physicians are usually the first source of information but may have limited knowledge about a rare disorder.

Organizations such as PACER Center and those focusing on specific disabilities produce publications and videotapes about disabilities. Many organizations have Web sites linked to PACER’s ([www.pacer.org](http://www.pacer.org)).





## 2. Build and continue good communication with the child's mother and other family members, such as grandparents.

Despite hectic schedules, the Guthmanns, Kempfs, and Walkers maintain frequent family communication. Telephone calls, e-mail, and family activities can keep couples in touch with each other and their children, in addition to providing avenues for coordination.





### 3. Spend time with your child.

The fathers create opportunities to be with their children. Through regular interaction with their children, they have developed appreciation for Alex, Patrick, and Malcolm as persons with gifts and strengths of their own.





## 4. Make necessary adjustments in your child's physical environment.

Fathers, particularly those who are handy with tools or knowledgeable about construction, may wish to create or obtain adaptive equipment or make their home more accessible for their children with disabilities. Some adaptations may be simple, one-evening jobs, but others may be major. The Guthmanns, for example, determined several years ago that their two-story house would not work with Alex and moved to a single-level home.







## 5. Find or create support.

Support designed specifically for fathers of children with disabilities is rare. A father wanting to connect with other fathers must seek them out on his own. John said that his involvement in disability organizations introduced him to other fathers with similar interests and concerns. As a result, he helped form a support group of eight fathers, which meets regularly.





Paul visited the meetings of a couple of disability-specific organizations, but he found they did not meet his needs. In the fall, he plans to attend a support group through one of Patrick's physicians. "Families, friends, and co-workers are another source of support. Let people help," he advised. When Patrick was born, the Kempfs were astounded by the breadth of kindness shown to them. "Many people want to help, and families can use it," Paul said.

Brian is active in his church and has developed meaningful friendships and support there. In addition, he served for several years on PACER's Board of Directors, with other parents of children with disabilities.



## 6. Enjoy your child.

“Patrick is who he is,” said Paul. “I don’t feel a need to constantly diagnose him—to find others like him. I find myself being pleasantly surprised by Patrick’s abilities as time goes on.” Added Jacque: “We’ve redefined ‘perfect.’”





# Siblings



Stop here and instruct participant(s) regarding outside assignment as directed in the *Roadmap for the Journey-A Trainer's Guide*.

10.6 *What Siblings Would Like Parents and Service Providers to Know* - By The Sibling Support Project of the Arc of the United States